
Indiana Protection and Advocacy Services

2011 Critical Barriers Survey Report of Findings

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Report of Findings

Introduction

In the summer of 2011, The Indiana Protection and Advocacy Services (IPAS) contracted with the Center for Planning and Policy Studies (CPPS) at the Indiana Institute on Disability and Community (IIDC) to conduct a survey of Indiana residents, to help identify critical barriers that IPAS should consider targeting in their advocacy efforts in the coming years. Specifically, IPAS wanted to learn what barriers Indiana citizens believed, that if eliminated or reduced, would enable people with disabilities to live, learn, work, and participate in their communities. The 2011 web-based survey approach is similar to the survey conducted in 2006 by CPPS.

The instrument used for collecting this new data in 2006 was refined for this 2011 survey. Most of the questions used in 2011 were the same as in 2006, but some of the answer choices were expanded because of the results from the 2006 report of findings. See Appendix A for the survey instrument used for this survey.

In the 2006 Critical Barriers survey, one hundred and fifty-five (155) individuals responded from forty-nine (49) of Indiana's 92 counties (53%). One aim of this new survey was to gain a better representation of the geographic nature of Indiana and to see what new priorities Indiana citizens might have concerning barriers to living, learning, working, and participating in their communities. The goal for the number of responses for 2011 was determined by IPAS and was set at 400 responses, from at least 80% of Indiana counties. As of January 25, 2012, the total number of respondents to this web-based survey was five hundred and five (505) participants from 87 of Indiana's 92 counties (95%).

Research Staff at CPPS expanded recruiting for this 2011 survey. Recruitment included emails sent to contacts in 54 Indiana disability organizations, postings on several major Indiana disability websites, the use of social media, and use of a mailing list housed at CPPS. Personal phone calls were also made to major disability advocates, asking them to forward the survey announcement to their mailing lists.

Staff monitored data collection and validated the data as it was being received. For this draft report, the results are presented for the entire set of respondents, which totaled 503. The number of respondents varies from question to question. In the report charts, an "n" is listed for the number of people responding to that particular question. Of the 505 respondents to date, 307 were people with disabilities or their parent/guardian, and 198 were professionals in the field of disabilities or another professional.

The survey contained five categories of services and supports for people with disabilities in Indiana, along with sub-categories of potential barriers in that category. For each category, the following question was asked: "If IPAS could work on only three barriers in each category, which three would you recommend as priorities?"

The findings are displayed in chart form. In each area, respondents were asked to indicate their top issues that IPAS should consider in future planning and advocacy. The numbers and percentages in the charts represent the number of respondents selecting each item as a priority.

1. CATEGORY 1: ABUSE AND NEGLECT

This category included the following barriers: Working to reduce incidents of abuse (i.e., abuse as perpetrated by staff members providing services to individuals with disabilities) and neglect is a primary function of IPAS. Experiencing abuse or neglect represents a fundamental barrier to living an independent and productive life.

Respondents were able to select up to three barriers that they believed IPAS should address in their next five-year plan. The chart below represents the frequency of responses to each barrier. The percent figure shows the percent of respondents who chose that particular barrier as one of their top three choices.

In summary, for the category of ABUSE AND NEGLECT, respondents indicated the following barriers were priorities for IPAS to address:

- Physical/sexual assault or harassment
- Isolation/seclusion
- Financial exploitation or coercion

Below are the frequencies for all the barriers in this category:

Abuse and Neglect	Frequency of Selection	%
Physical/sexual assault or harassment	241	48%
Isolation/seclusion	196	39%
Financial exploitation or coercion	173	34%
Personal care (hygiene, clothing, food, shelter)	161	32%
Verbal abuse	158	31%
Personal rehabilitation/vocational programming	149	30%
Inappropriate/excessive use of medication	139	28%
Inappropriate/excessive use of physical restraints	113	23%
Release from institution	54	11%
Suspicious death	29	6%
Other abuse (please specify)	40	8%

n =503 - * Percentages equal more than 100% because respondents could choose up to three.

Text responses from the "Other Abuse" question:

- Abuse of all types at school by other students and or school staff.
- Access to all stores with scooters
- Affordable, accessible housing
- Bullying, which is different from harassment
- Bullying
- Constitutional Freedoms
- Hidden disabilities such as mental and behavioral health
- Humiliation
- Law enforcement training
- Neglect of needs by state funding.
- Non Representation
- Not enough staff to care for them
- Not letting her dad have water to drink.
- Parking and structure barriers in the county
- Reduction in funding
- The decrease of hours by the state for the waiver program
- Threats and intimidation used to control and force into certain submissive behaviors.
- Abuse by adult protective services through intimidation
- Access to mental health services for all school aged children
- Adequate living arrangements
- Available affordable housing, adequate health care: medical, dental, vision & counseling
- Lack of resources no staff parents both can't be involved WHY
- Lack of support
- Looking and keeping a job
- Neglect
- Neurosurgery
- Police mistreat disabilities
- Refusal of staff to take people into the community
- respect (human values)
- Threatening an individual to get compliance
- Work/job related discrimination
- Being recognized as having a disability. If your Dr. says you are disabled that should be good enough to get financial help and support.
- The criminalization of youth with disabilities in Indiana's public school system. Especially regarding the disparate mistreatment of Black boys and children of color. I would also like to include the retaliation and reprisal that children and parents encounter from school officials.
- Refusal to provide interpreter, to provide culturally accessible services for the deaf to avoid isolation.

2. CATEGORY 2: TREATMENT RIGHTS

This category included the following barriers: Individuals with disabilities have the right to receive appropriate treatment that should be designed to maximize the potential of the individual and should be provided in the setting that is least restrictive of the individual's personal liberty. Failure to receive appropriate and effective treatment that is provided in the least restrictive environment represents a fundamental barrier to living an independent and productive life.

Respondents were able to select up to three barriers that they believed IPAS should address in their next five-year plan. The chart below represents the frequency of responses to each barrier. The percent figure shows the percent of respondents who chose that particular barrier as one of their top three choices.

In summary, for the category of TREATMENT RIGHTS, respondents indicated the following barriers were priorities for IPAS to address:

- Failure to provide appropriate mental health treatment
- Failure to provide appropriate medical treatment
- Admission to residential or inpatient care

Below are the frequencies for all the barriers in this category:

Treatment Rights	Frequency of Selection	%
Failure to provide appropriate mental health treatment	317	65%
Failure to provide appropriate medical treatment	271	55%
Admission to residential or inpatient care	156	32%
Diagnostic/other medical evaluations (not treatment)	151	31%
Diagnostic/other mental health evaluations (not treatment)	141	29%
Discharge planning	115	23%
Written habilitation plan	113	23%
Commitment/Recommitment	66	13%
Other treatment rights (please specify)	54	11%

n=490 - * Percentages equal more than 100% because respondents could choose up to three.

Text responses from the "other treatment rights" question:

- Area 7 Aging lie to us about available services and refuse to honor transfers
- Behavioral Treatments
- Consent for treatment
- Emergency Placement

- Failure to provide access to communication via sign language for Deaf or HOH patients
- Failure to understand an individual has costly care that is impossible to live out-of-poverty.
- Follow up with discharge planning and implementation
- Indiana's reduction of approved medication and services
- Labor related issues
- Medicaid reduction in hours of habilitation therapy vs. Dr. orders
- PWDs having access to all medical options afforded to ABs
- Plans not implemented appropriately
- Right to provide appropriate education
- Referrals
- Staff cuts through state Medicaid waiver budget cuts.
- Sufficient staffing
- Transportation for treatment
- Uninformed staff
- Vocational rehabilitation (VR)
- Adequate funding for treatment
- Community connections
- Community reintegration and involvement
- Continued care and follow up
- Cutting the waiver hours also cut valued staff from my life
- Dental
- Doctors fail to provide an interpreters
- Failure to provide support services to live independently
- Funding for DME
- Health care professionals who are knowledgeable re: special needs populations
- Inappropriate medical treatment
- Information on other options
- keeping the parent informed while child is inpatient
- Need more in-home services
- Neglect from care takers took parents out strangers steal take her meds etc.
- No interpreters for meetings
- Person directed treatment
- Quality of life recognition
- Right to good teeth and/or glasses
- Schools ordering parents to get guardianship
- The right to refuse mind altering medications that pose serious risks and side effects
- There is no BDDS residential care for the deaf-they isolate the deaf in hearing residential care.

- To live with family
- Various therapies-especially speech
- Limited choices in getting treatment because so many doctors, especially psychiatrists, do not take DD clients and/or clients who are on Medicaid
- Providers must be required to take Medicaid; otherwise there are no diagnostic services or treatment for persons with disabilities.
- Listening to the Parents and family about discharging home with home care, even private, and family care givers vs. going to a nursing home/"rehab"
- Blind people cannot read medication labels privately or independently and may not be able to read discharge directions from a medical provider. This can lead to accidents. My privacy is violated when I must share my medical information with a sighted person. In some cases it may be very embarrassing to share medical information. There are devices on the market that will read medication labels but they are not covered by Medicaid or Medicare.
- If you can't work because of your disability and it takes 2 years to get a hearing for SSDI, how are you supposed to live, pay bills, pay for prescriptions. I have depression that needs treatment, but can't afford to get it, can't afford to take my medicine as I should.
- Appropriate amount of funding for individual to remain in own home and appropriate amount of support (Our 24 hour support for last 3 years is being reduced to 40 hours per week with only explanation of decrease in waiver funding)
- Assistance in finding funding to pay for treatments. Jumping through the red tape to get treatment.
- Insurance companies including Medicaid refuse to pay for prescribed medication and insist on it being changed.
- Day treatment programs that keep children in their community, their schools and their homes if at all possible.

3. (CATEGORY 3: EDUCATION)

This category included the following barriers: Students with disabilities have the right to receive a Free and Appropriate Education (FAPE). Education that is not appropriate to the needs of the student or that is not provided in the most integrated setting represents a significant barrier towards receiving a FAPE and ultimately to living an independent and productive life.

Respondents were able to select up to three barriers that they believed IPAS should address in their next five-year plan. The chart below represents the frequency of responses to each barrier. The percent figure shows the percent of respondents who chose that particular barrier as one of their top three choices.

In summary, for the category of EDUCATION, respondents indicated the following barriers were priorities for IPAS to address:

- Assistive technology services & devices
- Transition planning (from school to work)
- Individual Education Plan (IEP) Planning/development/implement

Below are the frequencies for all the barriers in this category:

Education	Frequency of Selection	%
Assistive technology services & devices	220	45%
Transition planning (from school to work)	203	42%
Individual Education Plan (IEP) Planning/development/implement	185	38%
Discipline/suspension/expulsion	136	28%
Least restrictive environment	128	26%
Functional Behavioral Assessment(FBA)planning/development/implement	120	25%
Physical access	84	17%
Individual Family Service Plan (IFSP)planning/development/implement	78	16%
Eligibility	73	15%
Multidisciplinary evaluation/ assessments	71	15%
Violation of procedural safeguards	61	13%
Other education (please specify)	41	8%

n=489 - * Percentages equal more than 100% because respondents could choose up to three.

Text responses from the "other education" question:

- Access to extracurricular activities
- Disciplinary action to teachers who refuse to implement an IEP
- Encouraging higher education
- Extenuating Health Circumstances
- Failure to follow or implement the IEP
- Financial assistance for post-secondary education
- GED (lack of access)
- Helping provide lawyers for due process/complaints most important
- IEP too general and not specific to the specific student
- IPE development and parent rights
- Indiana schools use of RTI to delay or define a student's eligibility.
- Lack of the same type of IT in classroom (i.e. smart boards) that nondisabled peers have
- Many hard of hearing students are not served under an IEP and slip through the cracks
- Too often parents are told "this is what we do" and then all other options are off the table
- Total lack of career planning
- Training programs while in school for job readiness once exiting school
- accessibility
- Continuing formal education beyond High school. 3 r's
- Early intervention
- Enforcement of what is in their IEP...all who work with them.
- Funding not adequate to provide needed services
- Grants are too demanding of our completion rate
- Lack of appropriate curriculum/courses
- Not applicable
- Parental involvement & recognition
- Participation in extracurricular activities; post-secondary education for the physically disabled
- Poorly trained teachers
- Stigma from teachers!
- Transition to higher education
- Transportation
- Vocational education
- To offer a continuum of services. Often times least restrictive is interpreted as full inclusion which might not be the best placement for learning.
- Failure to prepare students with disabilities for further education, employment, and independent living.
- The school depts. and agencies that provide services for children with special needs abilities should be there to evaluate and suggest what is possible for each child in each area of need during IEP/Transition planning--if more was done early, it would be less intensive and irreversible in high school--they have a

conflict of interest and count on parents trusting them to want these kids to reach their potential and that they are doing what they were educated to do--Parents should not be the primary enforcer--I have seen and become aware of many issues since my twins have been in high school -- being different is not tolerated and if your disability is not obvious it becomes a nightmare that lasts your whole their whole life because they leave high school without a diploma or the basic abilities to take care of themselves and are not dysfunctional enough to be institutionalized or eligible for assistance--it is a huge injustice to these kids that have potential in many areas and it causes numerous unnecessary problems for everyone when they leave high school.

- Parents allowed to sue the school systems if they disagree with the IEP and then claim compensatory damage to their children
- They took my son from a completely self-contained classroom and put him into what we consider a resource room w/ specials without transitioning him. he cannot handle it and they will not even discuss putting him back into a self-contained classroom b/c no other child in the district we are in requires it., also too he has been denied OT and lost a counseling service at school over the summer. The OT they won't reconsider because he was refusing to work w the specialist, even though he is older now and more manageable. The counseling he lost because the co-op disbanded and no one was notified about them losing services. We only found out about it because of an emergency case conference meeting that I (mom) and his grandma called.
- For deaf students, the quality of sign language interpreters leaves much to be desired. It is not good enough to have a certified interpreter; interpreters must be qualified.
- Appropriate and current testing in development of IEP (i.e. use of 2nd grade assessments for high school student's IEP development stating the 2nd grade testing is still "appropriate"
- School refusing services by claiming they have no staff/money/time to provide extra one on one help to their students succeed
- Lack of support once a VR plan has been established, lack of counselors in college setting that work with special needs students

4. (CATEGORY 4: ACCESS TO SERVICES)

This category included the following barriers: Individuals with disabilities have the right to a wide range of services and supports. The lack of appropriate services and supports, provided in a manner that maximizes potential, and is provided in the setting that is least restrictive of the individual's personal liberty or reduces the choices open to people with disabilities about where they live, work, and play. Lack of basic services represents significant barriers that can result in isolation rather than full integration and inclusion in the mainstream of society.

Respondents were able to select up to three barriers that they believed IPAS should address in their next five-year plan. The chart below represents the frequency of responses to each barrier. The percent figure shows the percent of respondents who chose that particular barrier as one of their top three choices.

In summary, for the category of ACCESS TO SERVICES, respondents indicated the following barriers were priorities for IPAS to address:

- Community living
- Mental health care
- Personal assistant services

Below are the frequencies for all the barriers in this category:

Access to Services	Frequency of Selection	%
Community living	270	55%
Mental health care	218	44%
Personal assistant services	213	43%
Access to government services	187	38%
Assistive technology devices and services	185	38%
Person-centered planning	156	31%
Inclusive child care	75	15%
Interpreter service	51	10%
Other access issues (please specify)	48	10%

N=491 - * Percentages equal more than 100% because respondents could choose up to three.

Text responses from the "other access to services" question:

- Accessible transportation
- Access to integrated, affordable and accessible housing
- Adequate funding for enough services
- As a person ages so does the cost of care. Hidden disabilities become controlling.
- Case Manager who understand government services.

- Emergency Preparedness/Sheltering
- I can't click on most of these because I haven't even heard of them if that tells you anything.
- IPAS is never available for Vigo County concerns when needing protection!
- Lack of access to individualized community services due to cut backs in Medicaid waiver budgets
- The entire Terre Haute, IN area is horribly lacking in service providers from speech to ABA/FBA.
- Transportation
- Transportation for services
- We need dependable transport for our "disabled"
- Accessible public transportation
- Affordable accessible housing
- Community attitudes
- Community integration
- Employment
- Employment supports
- Guardianship as needed
- Health access, educational access, denial of access in reaching your fullest potential.
- In general lack of money to provide services
- Individual awareness of services
- Lack of case managers/advocates to insure continuation of services
- Legality of workplace/workers compensation issues
- Oral language facilitator for deaf children who listen and speak
- Poverty
- Resource room staffed by qualified personnel
- Technology available but not available to persons without resources to pay
- Transportation
- Transportation services
- Waiting lists are too long
- Well trained staff
- Qualified mental health care (hiring folks with high school diplomas, lack of MD/PhD and MS/MSN making diagnoses)
- Took the right for both parents to be staff we need jobs but are expected to provide care for free how do we pay our bills? Welfare people get more rights and they are capable of working.
- Accessibility to each and every public accommodation and business in the state as per the ADA titles II and III
- Printed information should be provided in alternative formats such as Braille, audio, large print, or on an accessible web site that can be used by screen readers.
- I don't know what services are out there for me, and I have done search's on the internet, then if you apply you either are not eligible because you make just barely over the limit, or the waiting period is so long it's a joke
- Blind people need printed information in alternative formats such as Braille, audio, large print or on an accessible web site that can be used by a screen reader. Many agencies still do not comply.

5. (CATEGORY 5: OTHER RIGHTS ISSUES)

This category included the following barriers: Various state and federal laws, rules, and regulations provide individuals with disabilities access to appropriate services (e.g. reasonable accommodation). Lack of information regarding these rights can represent a significant barrier to living an independent and productive life.

Respondents were able to select up to three barriers that they believed IPAS should address in their next five-year plan. The chart below represents the frequency of responses to each barrier. The percent figure shows the per cent of respondents who chose that particular barrier as one of their top three choices.

In summary, for the category of OTHER RIGHTS ISSUES, respondents indicated the following barriers were priorities for IPAS to address:

- Medicaid or Medicare issues
- Health care
- Employment: disability discrimination

Below are the frequencies for all the barriers in this category:

Other Rights Issues	Frequency of Selection	%
Medicaid or Medicare issues	174	36%
Health care	148	30%
Employment: disability discrimination	147	30%
Access to transportation (ADA)	109	22%
Accessible housing (ADA/Fair housing)	108	22%
Subsidized housing (Section 8)	86	18%
Public accommodations	81	17%
Problems with guardian/conservator	76	16%
Denial of recreational opportunities	69	14%
Architectural Barriers (ADA)	55	11%
Consumer or family participation in treatment planning	47	10%
Denial of parental/family rights	40	8%
Other personal decision making issues	39	8%
Denial of privacy	39	8%
Breach of confidentiality (of records)	32	7%
Other housing Issues	26	5%
Use of accessible parking	24	5%

Other Rights Issues	Frequency of Selection	%
Denial of access to records/corrections	22	5%
Use of service animal	20	4%
Voting	20	4%
Failure to obtain informed consent	16	3%
Denial of visitors	10	2%
Do Not Resuscitate (DNR) orders	8	2%
Advanced directives	7	1%

n=488 - * Percentages equal more than 100% because respondents could choose up to three.

Text responses from the "other rights issues" question:

- Disaster Planning
- Employment
- IDEA 2004
- Issues with transportation
- Lack of availability of guardians when individuals needs assistance in decision-making
- Sufficient staffing
- We are having major issues w the school
- Autism
- Disinterested staff who prefer to "stay home" rather than take a person into the community
- Family involvement and cost for recreation
- Flying
- Info related to assistive technology
- Interpretation of already passed laws
- Post-secondary education
- Public accommodations for those who wear hearing aids (ex. loops for FM systems, captioning)
- safe transportation
- Getting a job should be a more important right than right to minimum wage. We should allow waiver to minimum wage for workers that can never achieve even a small percent of minimum wage but need to be actually productive. \$1.00 an hour would be a great and fair wage for many of our target population.
- Denial of access to the Guardian who is attempting to advocate for the individual's safety and protection
- Conflicts of interest regarding schools that have doctors contracted with Medicaid doctors and state agencies
- Removing a child from SSI early which prevents them having health insurance, educational assistance, etc. because of a disability that haunts them into adulthood. Without treatment it affects them the rest of their life!!!

5a. If the respondent selected "Other Housing Issues" (in the above list), they were asked to please specify:

Text responses:

- Ability to find suitable housing and housemate
- Affordable and Accessible
- Attempting to obtain assisted housing
- Disaster Housing/ Recovery from disasters for People with disabilities
- Finding affordable decent housing
- Lack of available housing
- Many landlords refuse to rent to those with disabilities
- Provide Waivers for Supported Living based on urgent need.
- Access to Medicaid waiver funding
- Affordable housing
- Assistance to caretaker/spouse
- Availability of housing choices for families with disabled parents
- Available, affordable
- Cut hours means I may have to move back home with parents, I do not want to
- Discrimination by landlords
- Lack of housing for families with disabled parents with children still at home
- Low cost accessible housing, group homes, etc.
- Need for supervised housing for higher functioning disability
- Never found roommates for Medicaid Waiver home let alone appropriate staffing
- Not enough room, only one way out of residence
- Sudden decrease in 24 hour support so that my 61 year old Uncle with Down Syndrome can remain in his own home reduced to 40 hours per week due to decrease in funding for DD Home and Community Based Waiver
- Housing for those with very low income and in need of assistive living instruction with social worker.
- Creating more affordable, accessible housing in communities close to bus routes, grocery stores, and pharmacy's rather than segregated them in a separate community
- Unreasonable budget cuts that force people with disabilities to live where and how the state wants them to live.
- 4 people in one house with caregivers. Not enough space. no air conditioning in locations of hot humid summers, housing very costly for people living below poverty, cannot have pets,

5b. If the respondent selected "Other Personal Decision Making Issues" (in the above list), they were asked to please specify:

Text responses:

- Access to advice in wills
- Ability to live with family while receiving Medicaid waiver services.
- Client should make decisions!
- Credit issues to buying things he can't afford.
- Help with vocational rehab
- Lack of Qualified Guardians
- Legally recognizing a personal advocate appointed by the individual when served by an agency
- Making decisions based on the individual's needs, not a policy directive.
- Opportunity to make their own decisions
- Sufficient staffing
- The right to use or refuse artificial birth control
- Adequate supports in meaningful employment
- Being allowed to choose what they want to do
- Help in planning for independent living & employment
- Help with payee responsibility other than family members
- Laws have changed and don't know how to use
- Legal support for decisions for individuals not needing a guardian
- Relationship issues, parenting issue, divorce, separation
- Rights to decide for personal self
- Rights to have any relationship they want
- Self-advocacy and the right to make everyday living choices for oneself
- Sometimes the decisions my son makes are not to the best of his welfare
- Ability to make independent decisions when possible and to hold clients accountable for their freely chosen decisions
- My Uncle has a person centered plan that heavily reveals his desire to visit his family both in his home and their homes but his provider has suddenly decided that he shouldn't be out of his house visiting so often. They stated he needs to be in his home!
- Ability to decide what they wish to learn or high school class elective ability to participate and take.
- Parents/guardians making the decisions without taking into consideration what the adult child with disabilities want - not allowed to self-advocate.
- People with autism even high functioning should have a social skills or life coach at their side to access on a daily basis.

6. What do you see as the one greatest rights barrier for you, your family member, or for those you represent? (open-ended)

Text responses:

- Waiting lists are so long that even IF you do qualify. Many die waiting for services.
- Access to the built environment
- Ability to get a job at even \$1.00 per hour. Job is more important than wage!!!
- Acceptance in the community.
- Access to ALL stores, sidewalks, curb cut outs & ALL Government buildings
- Access to Medical Care Funding for long-term care
- Access to affordable, accessible housing
- Access to appropriate public transportation
- Access to community-wide events
- Access to government programs
- Access to health care if they do not have a guardian
- Access to information, available housing, barriers to appropriate placements
- Access to Medicare, no doctor will give the initial physical
- Accessibility
- Accessibility
- Accessible Housing designed for full time Wheelchair users.
- Accessible housing
- Accessing medical care with no insurance
- Actual Gainful Employment
- Affirmative action
- Affordable access to health services
- Affordable accessible housing
- Affordable quality accessible housing and daily oversight for meds
- Affordable, accessible housing
- Affordable, accessible transportation
- Affording housing and getting an education
- Attitude of inclusion
- Attitudes and ignorance.
- Attitudes of professionals
- Attitudinal misconceptions about the abilities and capabilities of people with disabilities.
- Being able to have access to public Transportation in the evenings and Saturdays
- Being on a level playing field when it comes to employment opportunities.
- Being seen as capable.
- Both of my Sons have special needs (autism) I am the only advocate they have.

- Budget cuts to Medicaid waiver, specifically staffing hours
- Business that have limited handicap accessibility.
- Community-based care options and funding
- Continued reductions in available funding
- Correct and consistent diagnosis
- Discrimination
- Education - administration not following IEP and failing to work with parents
- Education, Employment, access to technology, transportation, fair housing
- Educational based
- Emergency Planning for people with disabilities
- Employment
- Employment and Transportation - allows to function in the community
- Employment and equal pay
- Employment barriers
- Employment discrimination
- Employment opportunities
- Employment opportunities are few and pay poorly
- Employment. No job, no money, no outside interaction, complete dependency on SSDI
- Equal Treatment...
- Equal opportunities
- Equal treatment from providers. Favoritism to Preferred Clients
- Evaluation and acceptance
- FBP not followed while child has been in school now in High school
- Finding good direct staff for behavior issues
- Finding the resources that are relevant to present and future needs.
- Funding
- Funding for needed services/equipment.
- Funding.
- Getting Medicaid
- Getting medical care, mental health care and therapy for children 3 - 6 year olds.
- Government restrictions on services that are needed in order to save money
- Guardianship issues limiting freedom of choice.
- Having a say in their care and where they want to live.
- Having an inordinately long wait for the Medicaid Waiver
- Having someone who can help with major behavior issues?
- Having the correct care needed for each individual
- Health services

- Housing
- I lost my employment with the City of East Chicago as a direct result of my disability.
- If employable, employer discrimination. The ADA is not enforced.
- Ignorance/lack of knowledge in rural communities
- Inability to serve all those who need to be served.
- Inadequate level of mental health care treatment
- Inadequate mental health services
- Inclusive education and community
- Independence through accessible transport
- Information and informed staff
- Insufficient funding for adequate services.
- Insufficient t funding for residential services
- Insurance available after retirement before age 65
- Intentional omittance of other options in planning disability and/or educational services
- Jobs
- Judges not familiar with disability Gov. Programs
- Knowing the right people to contact
- Knowing what services a person is entitled to.
- Layers of bureaucracy and phone lines between them and public services in a remote location
- Lack of ADA accommodations
- Lack of adequate mental health counseling and treatment
- Lack of affordable assistive technology.
- Lack of care providers in our area - Ripley/Franklin counties
- Lack of education and awareness for the public
- Lack of education of services, eligibility and right to appeal when eligibility is denied
- Lack of funding
- Lack of general community understanding of needs of persons with disabilities
- Lack of housing and housing assistance
- Lack of inclusive programing in schools.
- Lack of inclusive/person first attitudes concerning education, transition, and employment
- Lack of information concerning available assistance
- Lack of listening systems that are working in public places for the hearing impaired.
- Lack of opportunities and preparation in preparing our children for the world after school.
- Lack of skills knowledge about rights by consumer
- Lack of suitable employment
- Lack of understanding and applying the corresponding legislation
- Lack of understanding when dealing with intergenerational support providers.

- Learned helplessness
- Least Restrictive Environment
- Length of time to obtain services or adaptive equipment
- Limited access to education opportunities
- Limited access to health care.
- Limited to no Education Resources to assist classroom teachers in small middle schools
- Literacy and comprehension
- Loss of services through a waiver that allow independence.
- Loud places, loud classrooms, loud movie theaters - can't hear with unilateral hearing loss
- My child is not seen as a future functioning member of society.
- Many services are provided for urban areas but not available in rural areas
- Medicaid Waiver list is so long, we will be dead before she will get services.
- Medicaid eligibility issues
- Medicaid issues
- Medicaid time limits for inpatient mental health care.
- Medicaid waivers
- Medicaid waiver funding
- Medicaid/Medicare issues
- Medical professional failure to provide an interpreters for the deaf
- Medical providers not knowing and giving wrong medication
- Mental Health Services
- Mental health
- Mitch Daniels and FSSA's ever changing policies and procedures
- Money
- My Son won't be able to drive, and we live in a rural area.
- My children's acceptance
- No legal representation for when rights violations occur by no one for them on SSI
- Not applicable at this time.
- Not enough staff to meet needs
- Ongoing Functional Service Needs above and beyond Education
- Parking for vans and architectural barriers and not enough housing for disability
- Personal care during work hours.
- Pervasive disability discrimination
- Physical accessibility
- Places that have limited handicap accessibility.
- Planning for future/ beyond school
- Privacy

- Public attitudes/awareness
- Reasonable cost for Interstate transportation for work
- Receiving appropriate hearing services
- Redundant bureaucratic paperwork/process
- Reintegration into the community via social, recreational, vocational activities
- Right to a chance at competitive employment
- Right to appropriate medical treatment and follow up; particularly mental health issues.
- Right to have accessible, affordable housing.
- Rights to a private education with the same services as public (i.e. aids, tutors etc.)
- Sharing of information causing more paper work
- Shortage of Interpreters
- Special needs exercise
- Staffing hours
- Staffing persons neglect of providing meaningful programs and inclusion.
- Stigma of the public against mental illness
- Substance abuse treatment
- The need for disabled housing.
- Terrible communication with providers
- That I am physically handicapped is the major issue in obtaining gainful employment.
- The complete disregard of accessibility to goods and services in public and private facilities
- The constant change in case manager
- The costs for service keep going up, but I am being cut money from my budget
- The long wait for DD waivers
- The potential for abuse/neglect whether with family or outsiders.
- The right to fail
- The school system and lack of good health insurance coverage
- The state telling us where and how to live.
- The stinking government (local & State).
- Therapies that are available and appropriate
- They need jobs
- To have our opinion matter and follow through.
- Transition from school to work is the greatest barrier facing students.
- Transportation
- Transportation which can produce to employment and leisure activities
- Under funded public programs, services, facilities, etc.
- Understanding what is available in the community to assist them.
- Universal Design

- Waiver Services
- Working past the sense of entitlement
- A truly inclusive appropriate education with high expectations of success
- Acceptance
- Acceptance, look at as person, not disability
- Accessible transportation
- Accessibility
- Access to accessible and affordable housing
- Access to affordable, community based housing
- Access to augmentative communication
- Access to employment and related accommodations
- Access to governmental services
- Access to information
- Access to mental health services
- Access to mental health/mental health assessment
- Access to public services, it is a maze of different eligibilities
- Access to services
- Access to the latest prosthetics technology.
- Accessibility to functions that would be beneficial to him
- Accessibility via technology
- Accessible and affordable transportation
- Adequate affordable transportation
- Adequate care
- Adequate transportation
- Affordable, accessible housing
- Age of parent/guardian
- Appropriate education
- Approved amount of services provided.
- Architectural and attitudinal barriers in education
- Attitude
- Availability of mental health providers for individuals with communication deficits
- Availability of mental health services, health care services
- Available funds
- Budget cuts that isolate the client
- Building access for handicapped
- Community access
- Community living

- Confidentiality and rights of humans
- Continued assistance without parental involvement
- Daily living assistance
- Denial of insurance coverage for prescribed therapies and nutritional treatment
- Denial of waiver services because budget is supposedly too high
- Discrimination
- Discrimination against mental health consumers
- Doorways not big enough for my Rollator
- Education
- Eligibility for services
- Employment
- Employment for individuals with intellectual disabilities
- Equality in school; not putting child's and family's best interest first
- Excessive wait list for Medicaid services
- Failure to comply with the ADA in general
- Fair medical treatment for brain issues
- Fair treatment and lack understanding by employers and other employees
- Family participation in treatment planning
- For not providing interpreter for effective communication
- Free or subsidize housing for disabled people
- Funding
- Funding for guardianship and restraint in requiring it by schools and DOH
- Funding sources to provide employment services and shortage of staff
- Have a good life and know what you want
- Having direct communication, as guardian, with service providers. When
- Health care treatment
- Housing that is appropriate and affordable
- How and where to get started
- Ignorance of others
- Information and receiving of waiver services
- Informed access to public offices for Deaf and people with all disabilities at BMV
- Informed choice
- Lack of accountability (noncompliance) of school districts & personnel
- Lack of active treatment of goals, plan of action etc.
- Lack of affordable health care
- Lack of available affordable and accessible housing
- Lack of awareness of the potential of people with disabilities

- Lack of employment opportunities
- Lack of employment opportunities & supports for individuals with Developmental Disabilities
- Lack of flexibility of waiver funding
- Lack of funding for supports
- Lack of help to get involved in community
- Lack of medical care
- Lack of respect for individual differences by schools and community members
- Lack of service sensitive to the needs of transgender individuals with disabilities
- Lack of supports from the public school system to independent living
- Lack of treatment due to financial resources
- Loss of rights pertaining to incarceration
- Med
- Medicare cuts
- Medicaid
- My ignorance of choices
- Need for one on one tutors in public school system
- Not being able to be as independent as possible
- Not being treated with the same respect others receive due to disability
- Not enough funds to enjoy life, denial by Medicaid of prescribed medication,
- Not enough housing to accommodate a disability issue and unaffordable housing
- Parents not in agreement with least restrictive measures
- People not understanding the physical barriers of those in wheelchairs in all areas
- Physical access
- Physical barriers
- Proper funding for those in need
- Proper supports needed to live and function
- Public discrimination in regards to mental health
- Receiving an education
- Restaurant restrooms frequently do limit access
- Right to participate/have a say in decisions that affect them.
- Risk of abuse and exploitation
- School and mental health
- Services that are cut for people with disabilities
- Shortage of subsidized alternative day services for family members with dementia
- Society stigma
- The attitude of individuals who see the chair & not me, attitudinal barriers
- The inability of IPMG case managers to advocate for consumers

- The right to work
- The school systems don't always do things fast enough or efficiently enough in Indiana
- The state's push to take guardianship away from people with disabilities
- To be treated as an equal with all people
- Total access whatever disability
- Transition from school to the community
- Transitional services (from school to work)
- Transportation
- Transportation
- Transportation: IndyGo is not timely and taxi companies won't take IndyGo vouchers
- Treatment of people with disabilities as second class citizens
- Treatment with dignity
- Understanding
- Vocational school to work services for family member, no career counseling, etc.
- No agencies will assist when help is needed (everyone "passes the buck" and the family is left with no help to support their loved one with a disability).
- Many Medical In- home service providers allow workers to steal from those who truly need the services. I have had a relative where this occurred more than once. It appears they do not check out people they send to the homes, who need the services and are vulnerable. Something needs to be done, if they are receiving state money.
- Access to printed material and web sites that are not accessible by screen readers used by the blind.
- There are a couple....Medicaid waivers for graduates to be approved and the long waiting list for the help.
- The numerous ADHD kids, with executive function deficits, in schools that are not getting the accommodations they need to succeed, not qualifying for IEP's.
- Others deciding for the individual what is best for them, without the individual being involved (even when well-intentioned)
- Need more affordable therapy programs for children preschool age. Insurance limiting how many therapy sessions you get per year
- All public facilities should be accessible for the deaf community. In Allen County there is not one movie theatre that is deaf friendly, having open-captioning devices so we can understand what is being said. Bones in Columbia City and another cinema in Indianapolis have such devices.
- I am the healthcare representative for my mother, but at nursing home she resides in, the patient has right to refuse showers, cleanliness - I don't think this is right because of bacteria, germs, etc. I, myself, give her shower w/help of CNA and it works better - because she cannot refuse me. My mother has dementia, and still knows she has rights, but I don't agree with this one. Also I know patients cannot be restrained, but I have seen patients fall out of wheelchair onto the floor because of this.
- For people to place the "Best Interest" of the person with Autism as the top priority before considering anything else.
- The most significant barrier for me has been the Med Works program. I am constantly under review for benefits and due to the high turnover rate amongst the case managers at the FSSA office, paperwork gets misplaced. Then my benefits are terminated without a phone call or letter. I have spoken with three different case managers this month and I was told today that there are no records for any of the calls I made. I only found out my benefits were canceled when I went to my doctor and was told that I did not

have Medicaid benefits today, even though I had already paid my monthly premium. It is so upsetting to me that when I called the office, the case manager laughed at me and said, well, it looks like you are going to need to reapply for benefits, all because my previous case manager didn't enter notes in the system from our phone interview, and instead decided to just close the case.

- Failure of employer to give reasonable accommodations. Disclosure of personal issues to people who do not need to know.
- Not enough qualified people with disabilities in the decision making process which are disability sensitive.
- Tim is punished for living with his mom by cutting needed services and not assigning services correctly.
- Right to a job. I have qualification when in interview they see I am blind and they are not willing to hire me even though I am qualified.
- I am part of an advocacy group in Fort Wayne. The greatest barrier I see is those individuals don't give in the right to exercise their rights.
- Access to early intervention and treatment for children with emotional, behavioral, mental health concerns.
- Employment- having a job to afford cost of living benefits, felony background for people with disabilities
- The DFR's and other services i.e., FSSA etc. are sorely mismanaged and despicable in the ways they go about doing their jobs.
- Employment. I have been trying to find a job but because of health issues I haven't found anything. I need to work a part time job because I can't handle more than 4 hours a day. Plus to do some jobs I need training. I'm a nurse and can't work in that line due to physical disabilities.
- For our son, transportation is a big barrier. When looking for jobs, he cannot consider all shifts due to transportation not being available.
- Seeing that there are a lot more transportation so that they can get to work and back home after work
- People in w/c not having adequate access to buildings, places of employment, event venues. What some people consider accessible really isn't.
- Not being eligible for services because of making too much money, but your child has a lot of medical costs and doctors' bills.
- Ease of access to and use of government-funded programs, such as First Steps, Medicaid and Waiver programs, food stamps,
- Government programs are clouded with rumors and misinformation in regards to access and how these programs impact or are impacted by outside programs like insurance or VA benefits.
- We are his Guardians and we can't stop him from buying things that he can't afford. We had a hard time to freeze his credit scores because he was over 18 years old.
- Communication with state agencies regarding benefits available, quality jobs in the community (not making pizza boxes), there are jobs disabled people can perform but society doesn't allow this to happen.
- The waiver does not allow for a consumer to live independently if they do not want a housemate. IPMG and the state are forcing folks to live together in situations and share staff when they don't want to live with anyone.
- Difficult for individual's in need to understand & go through processes of getting available benefits.
- Misunderstanding of inclusion. People wanting to segregate and/or "overprotect" versus allow rights & opportunities
- Funding needed services. All of the documentation shows my Uncle requires 24 hour in home support to stay out of an institution (he has always lived at home and never in a facility) and all of a sudden due to funding, we are told he is in real jeopardy of having to leave home at 61 years of age.

- Accessibility-interpreter rights for Deaf particularly the elderly. Those with dementia in assisted living or nursing home facilities. These folks have no way to advocate for themselves!
- Consistent and coordinated services, rules, guidelines & eligibility over multiple state/federal agencies
- Housing most of the HUD housing went to elderly and cut out the disabled as of October 2010, for 1 bedrooms
- Some staff treating our clients as children to be punished for "bad" behavior or not following their directions.
- Lack of adequate training programs designed to help blind and other disabled people gain employment.
- Being treated like I have no rights just because I have a diagnosis of mental illness. Not being treated with dignity and respect.
- Attitudes--so often staff believe that they have the right to make decisions for the individual; or believe that the individual is less important--inappropriate staff make an individual's life feel hellish
- Getting financial help with everyday living items, over the counter medicines and recreational outlets.
- Lack of a fair share of federal and state affordable housing resources for people with disabilities and older adults with very low incomes (e.g. SSI). People remain in nursing homes because cannot afford to move out without rental subsidies
- The funding system is not set up for independence since all budgets now require each person to have at least one roommate and new waiver recipients are required to have two roommates. These are all people who have developmental disabilities including difficulty coping and relating to others and they are required to live with perfect strangers.
- I have tried to find a job but due to the financial issues with Medicaid and social security, it's impossible to work. I can't afford to lose my social security (SSI) and Medicaid. I can't work over 6 hours a week or I'll lose everything. I'm physically capable of working about 10 to 12 hours a week unless my condition causes me troubles. I have some times when I'm not able to work as much due to pain and the physical ability. It can vary from day to day and I do understand that to hire someone who may have a day they can't work is a little hard but I still can work. It's a real problem for me.
- Medical issues being taken seriously. I am a large person, who several years ago, injured a knee. My treatment was to simply sit in a wheelchair for six months. I know of five other people, all more average in size, who had the exact same injury, and they all had surgery to repair the damage. It wasn't even discussed as an option with me.
- Refusing treatment of MI / DD patients in state hospitals, state funded community mental health centers and in local community hospitals psych units. Getting adequate mental health services for the MI/ DD client is impossible.
- Un equal access to services for the deaf and hard of hearing children who choose to listen and speak (rather than sign)
- IEP/complaint/Due Process not having funding for lawyer and not making county spec education co-op director do what their job is. We have had our 2 children w/o education for 4yrs still have one school age no money for lawyer and if we use an advocate IPAS won't help us
- Medicaid discriminates against Asperger's syndrome. They provide treatments for other disorders but refuse to provide social skills coaching to learn social skills.
- Many clients do not have the capacity to make phone calls to the Medicaid office and often have their Medicaid revoked do to either a miscommunication or a problem in the Medicaid office
- Necessary transition services while still in school, and then after completing school; particularly VR services and waiver services
- The state will not allow both parents to be a care taker. We can't get staff and we have to scrape by with no pay and provide care for free while state pockets the cash.

- Right to a job coach who has the time and vision to work on securing an appropriate job in the community in which the individual with disabilities can succeed.
- Enforcement of ADA in rural health care settings related to providing equal access to communication via a sign language interpreter
- I am a daughter of a deaf mother. We had to put her into a nursing home. It really upsets me that no nursing home provides a TTY or the video relay service. I have had to do all the work of setting up a video relay and getting the internet hook-up and also have to pay the bill. My mother had no communications with her other children for several months.
- The schools not placing our children where they need to be not where the school THINKS or WANTS them to be.
- Right now it is transition out of school and employment. The schools are not preparing adults with disabilities to exit out of high school and get a job, go to college, or other vocational training. Also supported housing is does not exist.
- Not receiving appropriate health care because of life expectancy is short and current health very bad. Getting transportation to doctors and others is very difficult and very expensive.
- That I have fibromyalgia. I have pain every day. I do have good days that I want to get out and do things, but scared I will lose or not get benefits.
- Affordable care, living in poverty yet working despite multiple physical and mental issues. Medication management is unaffordable.
- Clients that have guardians who make all the decisions but the guardians are "inactive" in the clients life
- The greatest barrier is lack of knowledge. Services, agencies, activities are out there, but they seem to be a well-kept secret. Providing people with disabilities with the information they need to successfully navigate through life should be the priority for all agencies, yet it does not seem to be.
- The lack of a case worker or advocate assigned to each disabled person to insure a smooth transition to adulthood, to educate families about rights and services, and to insure these services are provided appropriately and with quality over time.
- Lack of involvement of people with disabilities in the decision-making process, both at the policy-making level and at the individual level
- When we go shopping or to any other type of business, they do NOT have enough wheel chairs, motorized carts and they should have handicapped check out only lanes
- To be free from the re-institutionalization policies the State is currently engaged in - encouragement of congregate settings.
- Lack of understanding about disabilities among health care providers, employers, and other members of public
- When my daughter was sexually and physically abused, the law in IN said she was TOO BRIGHT and should have been able to get away from them. Her IQ is 62, she is MIMH and autistic.
- We are currently trying to get medical care for our foster daughter - she is denied Medicaid because she has a child and won't say who the father is because he is not involved and promises to be a problem if she gets him involved. She needs surgery, but can't get financial help to get it. She is disabled and lives on SSI, supporting herself and her child by herself.
- In this community, the buildings are already built, and cannot or they are unwilling to change to accommodate the handicapped.
- Access to services for an individual with mental health issues, living alone, in seclusion, in denial
- Getting lost or shuffled through the state/federal systems with no focus on the individual's abilities and no sense of recourse.

- I still deal with a lot of people out in the community who don't want to deal with people with disabilities. People who work in the stores and restaurants, etc.
- Inclusion in the community and educating the community on how to include individuals with disabilities
- For my family, the barriers would be the denial of basic human and civil rights. I am a mother who is Black and whose son happens to be Black. I see the discrimination he faces, not based on his hearing impairment but on the color of his skin. Being a Black boy that has been marginalized by white school officials has been his greatest barrier.
- That person with disabilities do not seem to have expectations placed on them to achieve, the learning curve is dropped. The expectation seems to always be there that they are owed something.

7. What would be the ideal solution regarding the greatest barrier identified in the above question?

Text responses:

- A clean, safe and suitable place where people on disability can afford to live.
- A dramatic change in societal attitudes especially hidden disabilities and mental illness
- A job that uses the skills and talents of an individual
- Access to mobility aids
- Access now instead of 11+ years on the waiting list.
- Accessible information in public places that people with disabilities can easily obtain.
- Additional money available.
- Affordable health insurance that provides full coverage
- Aide
- Allow more safe natural consequences
- An automatic assignment of such a person to each disabled person.
- Availability of more low cost public transportation
- Be more transparent in how funding is determined (since I know reductions need to be made)
- Better paid/trained providers
- Broad embracing of disability pride
- CMA coming in and telling FSSA to make a decision and stick to it.
- Churches and other community services offer hard of hearing services
- Convince schools that the ADA applies to them...
- Devote more money to this service so that this service can run a few more hours
- Don't cut the state funding
- Ease the restrictions and allow more people to be eligible for services.
- Educate people that just because someone has a disability doesn't mean they can't do something
- Educating school staff about article 7 and requiring them to be tested on the laws
- Education

- Education of public about mental illness & psych meds
- Education of targeted key leaders & community members
- Education to the community on hiring people with disabilities and pros.
- Enforcement of the ADA
- Enforcement of the ADADG
- Expansion of Voc rehab to include volunteer training, age appropriate social options
- Extended educational opportunities with transportation for increasing literacy
- Extensive training, education and empathy training
- Facility/gym with special needs exercise equipment
- Find other housing facilities for none full time wheelchair users.
- Finding the right people to contact
- First that they make this person with autism eligible for the list and then get her services.
- Follow ADA directive in all communities
- For public education about the needs of people with various disabilities
- For these individuals to receive enough funding for the services they need.
- Free and available Medicaid physicals
- Funding by foundations and the state or feds
- Funding for critical community services/self-directed support
- Generally believe this is a funding issue
- Get rid of both!
- Giving them a voice to speak that is respected like any other citizen.
- Good family participation and a community that welcomes differences.
- Greater information dissemination
- Hands on supports until capable in job whatever length of time.
- Having enough staff to provide adequate care for the individuals
- Having increased respite care services or other programming in place while on wait list
- Having my autistic son respected and treated with dignity by caregivers
- Hiring and training of staff
- Holding business/industry/government to the current laws
- I am disabled and I need my Medicaid so I can get decent health care.
- I don't know
- I think you should listen to the patient when he explain his problems
- I wish I knew the best answer!
- I wish I knew?

- I would like the same services as would a student in public education
- I'm not sure.
- Ideally, each person could live supported how they want to live.
- Improve collaboration of family and school therapists with outpatient services
- Improved education in related areas (i.e. Housing, transportation etc.)
- Increase funding for mental health facilities.
- Increase the funds
- Increase training of regular teachers in provision of individualized education
- Independent living with video observation and drop-in daily check for 30 minutes
- Individuals need to realize that individuals with a disability are still people.
- Inexpensive public transportation.
- Insurance would cover most of our costs.
- Jobs for the disabled
- Let the individual express input and be heard!
- Lobby for more funding for employment, supportive services and retention services
- Long term mental health with no time limit
- More awareness of people and their disabilities.
- Make it easier for disabled persons to get insurance
- Make some positive changes!
- Making it easier and less expensive for parents to advocate when the school isn't
- Mandatory training and standards
- Me having a car
- Medicaid should provide a clear reason when someone is denied benefits.
- Medicare, Medicaid and programs such as hip being available
- Mental health facilities in local communities that accept Medicaid
- Mental health therapy sessions of once per week to continue as long as needed
- Money to fund more waivers or system reform.
- More mental health services
- More providers in our area to choose from.
- More community outreach on disability awareness
- More education for everyone on disabilities.
- More flexibility in the use of staff hours over the year, more transparent allocation system.
- More funding
- More funding for section 8 and site-based income-based subsidization.

- More liberal income guidelines
- More opportunities for jobs
- More options and funding
- More prosperity
- More recreational opportunities, transportation, and services for residents in rural areas.
- More section 8 dollars for those with disabilities and more appropriate housing
- More section 8 houses available without such a long waiting period
- More services to assist in this area of life
- More subsidized housing and everyone getting proper evaluations
- More trained facilities that have options and solutions for children who have behavior issues.
- More training of teachers and allowing professional assessments of needs.
- More vehicles with extended hours
- More workshops that will teach real and marketable skills
- My children willing to acknowledge
- My own home, not an apartment
- Other than more money for the program I can't think of any
- Our son to have a budget that allows him to have 24/7 care that he must have.
- Outreach to community groups, PTO (Parent Teacher Organization), rotary etc. To educate
- Parent/guardian must agree what was said at the meeting.
- Pay me!
- Personal car
- Proactive advocacy that produces systemic changes
- Programs to help find employment, transition
- Provide more incentives to employ people with disabilities
- Provide more subsidized adult day care programs outside the nf(sic) setting
- Public education
- Public transportation for those in rural communities
- Public transportation in northwest Indiana
- Put you money where your mouth is
- Return to local representatives for social service programs (TANF, Medicaid)
- Re-fund Medicaid waiver to 2010 levels to meet the minimum needs of individuals.
- Redirect funding toward services, not bureaucrats
- Repeal the statute
- Requirement that Medicaid providers receive training in needs of transgender individuals

- Review need and provide emergency DD waiver
- Rural DSL Internet upgrades across Indiana
- Socialized health care
- Some kind of transportation changes, for all the disabled in our area.
- Something to make the courts recognize mental health instead of jail or prison
- Specialized training in this field for mental health providers and certification
- Stable/increased Medicaid waiver funding.
- State should fill vacancies as they occur so there are not gaps in service delivery.
- State should increase funds to level promised years ago
- Sufficient staffing and training for those working for Voc rehab and employment agencies
- Support services available within the classroom setting. Currently pursuing due process
- Talk to someone that can help me out with this barrier of transportation
- Team approach with schools, doctors, and parents
- That legal helps would there to truly help rather than make matters worse than they already are?
- That she would be granted Medicaid - not penalized because she chose to keep her child.
- Therapists travel to rural communities
- To allow disabled people to be inefficient in different ways, and to advocate for themselves.
- Training and access to a knowledgeable advisor who can coach and also follow up over time
- Transportation availability at all times of the day or night.
- Universal design of all housing
- We need more services such as respite, childcare for older children,
- When new buildings are being planned, have someone who is in a w/c give input.
- State should be as concerned for children's welfare as they are for school districts
- A case conference committee that looked out for children with special needs
- A punitive damages amendment to the law
- Acceptance of truly individual independent plans
- Access to community services and employment
- Access to discharge planning and re-entry resources
- Accessible taxis
- Adequate funding for programs
- Awareness training in schools as to the individual worth & value of PWD's (people with Disabilities)
- Being able to choose where he goes to school
- Better educate parents on why we use least restrictive measures
- Better education and better trained teachers

- Better guidelines, proper funding and training for schools
- Better handicap accessibility
- Can find one no one listens
- Change of Indiana law to allow for advocates (not just legal advocates) to assist people
- Club house or drop in centers integrated into community activities
- Consider those in need
- Continue services cuts should come from other areas in government
- Developers building additional affordable, accessible housing
- Disabilities have the same rights as other people
- Distribution of technology to those even if not working
- Don't know
- Educate others that we are not our disabilities
- Educating potential employers about the benefits of hiring individuals with disabilities.
- Education
- Employers willing to employ more employees of unique needs
- Enforce equal opportunity laws for individuals with disabilities
- Family not understanding the issues
- Financial help
- Fixed service routes in all areas of Marion county (i.e. Lawrence township)
- Fully accessible public transportation 24/7/365 with a reasonable cost for same
- Fully fund the Medicare system for disabilities first
- Get the case manager to do their job
- Getting committed staff for consumers
- Give individuals true choice not just this is who is in your area
- Give us Medicaid waiver services!
- Go back to person to person in the offices
- Government and business following rules for physical access
- Greater use of section 8 vouchers for pwd
- Group home personnel would transport them any time any place
- Having more cooperative "players" from VR and BDDS
- Help people become as self-sufficient as possible.
- Hiring more special education workers who spec. In autism
- I would like for any deaf person to have some help so they can call their families.
- Ignorance, prejudice, tolerance

- Improved monitoring of follow through; onsite observations.
- Incentives to get and keep staff, personal care, OT (occupational therapy), speech, music, hippo therapy, pt...
- Increase in subsidized dispersed, integrated housing
- Increased monitoring by case managers
- Individuals should have meaningful work upon exiting school
- Information sharing by agencies
- Informational meetings, education, public relations
- Laws changed to not allow lower than minimum pay for work
- Less government
- Let the responsible professionals do their jobs
- Making prosthetics affordable to all.
- More acceptance and training
- More awareness/education about what governmental services are available
- More decision making from the parents/guardians
- More funding
- More health care people that take Medicaid
- More mass transit infrastructure and options
- More public service education
- More rural or mass transit opportunities
- More work places willing to make accommodation
- One on one help or advocates to help
- One set of eligibility criteria for most agencies
- People being educated about mental illness
- People must speak slower
- Person directed budgets
- Personal assistant
- Powerful and ongoing campaign for disability awareness with high profile participants
- Provider education, stringent and immediate consequences for violation
- Quicker access to Medicaid waiver services
- Repair and reform into compliance
- Required education for consumer/employee and employer
- Rooms built for sound environments for people with hearing impairments.
- Some sort of uniform rules that make sense concerning location of handicapped parking

- Special programs to make alterations to existing housing
- Staff needs to take clients to do what they want to do.
- State funding for the IAGS project
- Strict ethical awareness
- Take people off that can work but obt not too
- Teach tolerance
- That neurosurgeons would be held accountable for surgery results
- To ensure each individual is matched with services for their needs.
- To stay in my own home with staff helping me
- Training and incentives for employers
- True respect and willingness to help all affected by mental illness
- Unknown
- Videophone
- What is available now
- Write in so people can understand it then you legaleeeeeeeeees
- Get more funding for VR to support improved programs to assist clients to gain the appropriate education and training to seek stable employment. Form commissions for specific disabilities to insure that said group can be served by a program which is knowledgeable about their specific disability. For example; a commission for the blind.
- Supports would be designed on an individual basis. As it stands, the vocational supports are geared primarily to an extremely low level of functionality.
- I believe, the ideal solution would have to be a moratorium on the placement of black boys in special education. Also it would be necessary to file a class action lawsuit against the state department of education for allowing this injustice to continue.
- A system by which employers have to inform state government they are considering hiring a person with a disability so the state can give them information on the different programs available to assist in making the employment of that person work
- Assistance with purchasing a wheelchair van in the form of a loan that is available to a person with very limited financial means and/or imperfect credit
- Medicaid would allow and pay for social skills coaching so individuals with autism can learn social skills. This would also save them a lot of money.
- More assistance for recreation, change what parents with disabilities can claim, reduce the amount of claimable medical on taxes. I have no health care. More support for adults with dd.
- A list of doctors that will give this physical and require them to give the physical to anyone seeking Medicare access.
- Education for BMV employees of accommodations and being able to get response without violating confidentiality of a client
- Requiring all business, regardless of the age of the building, to become handicap accessible to everyone.
- Independent living situations that support employment for individuals that can work and desire to do so

- The covered bridge special education district puts more time, money, and effort into fighting you on providing a free and appropriate education than if they simply provided the needed services to begin with!
- Insurance needs to let the doctor and patient/guardian decide what is best for them, which will help make them a productive member of society
- All students would receive a support services waiver upon graduation to give them a good start on obtaining community and employment services.
- Allow guardianship to expire after a certain amount of time and require guardianship to be reviewed for renewal
- A specific class/workshop for clients which trains and walks them through job search, interviews, career counseling, etc.
- For the governor and all that are involved to take in consideration all those who are in need of help that are disabled.
- Respect and teaching modalities toward increased independence. People doing things for someone rather than teaching them to do the task.
- Although size is part of the big picture, it cannot be the single deciding factor when it comes to treatments. Medical workers, from doctors to EMT's need to see the person as a person, and not as a tub of lard! Treat all who are legitimate in their complaints, and treat them the same as you would anyone else.
- That a "hot line" or other central place be established to investigate reports of non-complying with the ADA law regarding this.
- Information to detailing compliance and the importance of access to health information in a deaf or Hard of Hearing person's native language.
- Provide a state program that could assist those who do not know how to design an accessible web site or to help those to put information in alternative formats. The team should consist of persons trained in the computer science field and should have knowledge of the use of screen readers used by the blind. Agencies wishing to make their information available could call or get on site technical support.
- An initiative that wakes people up & helps them see past the disability and to the person and what they have to offer.
- If we could get city officials behind the change, building would be more likely to be changed to be handicapped accessible.
- The individual having the right to veto decisions being made about them, as long as it does not affect their health
- Being treated like "I" know what is best for me and "really" being listened to when I have a complaint or issue and that it is validated.
- Having loving, caring individual who treated our clients as their own family rather than ignorant human beings.
- Not have to fight doe to receive appropriate education. Or allow funding to be used at a different placement/ private aba
- There are so many fiscal constraints that I don't think an ideal solution exists in the current economy
- Increased training, more respect for the job staff do (but more requirements for who can be hired) and

maybe most important of all: random drug testing quarterly of all staff working with individuals with developmental disabilities

- Autistic people need advocates to help them access all the services they need and fight for their rights.
- When people with disabilities are being placed into a process, the person(s) that they deal with have at least a good understanding of the client.
- Affirmative action for qualified people with disabilities who are willing and able to work under the ADA. Reasonable accommodation standards.
- Employing disabled persons to check on these areas, like a secret shopper, and report their findings so things can be fixed and changed.
- Hire people that actually want to help people with disabilities, and make sure the people that already have these jobs are actually performing them, and not using every possible excuse to deny people services that they are eligible for and deserve to have. Like not returning phone calls, not answering the phone when people call, not leaving messages, taking weeks to process applications....etc.
- Making elderly able to receive Medicaid benefits with less difficulty and "red tape" and allow their families to receive inheritance rather than having to sign over what they have worked for their whole lives to the government. They want to leave things to their family but then it makes them ineligible for services because they have as little as \$200-300 too much in the bank??? Doesn't make sense.
- Individuals while in the hospital or other residential facility have an agency other than the board of health to look into complaints. However, once a complaint is made also make sure that the person making the complaint is in a safe environment where retaliation cannot take place. Hendricks County has a wonder transportation system for people in need, the senior center will provide transportation at no cost and take individuals to places the need and want to go. All counties need to have this type of transportation available for the aging and disabled. Hendricks is funded by united way.....
- If the eligibility reviews were given less often, case managers were carefully trained about the different programs, and if the case managers were polite with a consumer called and were able to address the consumer's concerns, I think we would be in a much better place. Also, if case managers would attempt to call the individual before turning off their benefits, this would really make a difference in the lives of individuals with disabilities.
- An ADHD-trained professional who is a student advocate in each schools system, who is not employed by the school system. Even a volunteer would be a huge step forward.
- More communication between agencies to work together for the good of the individual and not to merely pass issues on to the next one.
- Guardians have full rights over the money credit issues without having the ok from the disabled adult.
- Job coaches would rate a job at what productivity percent can the candidate achieve with regard to minimum wage. If \$1.00 is reflective of actual efficiency, compared to a typical worker then that is what should be paid. The fiction that some of our productive clients can ever achieve minimum wage levels needs to be discarded so that we can get our clients working. The punch line is that "they really don't need the money" since they have other sources of support.
- Funding for services like housing, food, insurance that is lacking for many disabled people who do not fall into the "right" category, but are disabled.
- Creating affordable, accessible housing in communities close to bus routes, grocery stores, and pharmacies
- Offer potential employers tangible monetary (tax breaks or wage subsidies) incentive to employ such individuals
- That my son is safe and I have help keeping him safe. I could keep him in the family home but still have

employees to give him care while I work. Medicaid only allows 5 hours of caregivers if your child lives in the family home.

- Rebalancing the institutional bias toward home and community care based options which are cheaper and provide better care.
- Apply design criteria of fair housing act to all new residential buildings including single family homes.
- Make sure people with disabilities are at the table from the first step of decision-making! And actually listen to what they want!
- School and community agencies need to work together more to ensure that students have something meaningful to do after they exit high school. Also community housing.do
- Continue to provide adequate staff funding to ensure that my son receives proper supervision. Without it he is a danger not only to himself but others as well.
- A compiled listing of available sources and a central application for funding available to support these needs without further individual application process.
- Shorten the waiver waiting list and find some way to lessen the process of appeals, letters of medical necessity, more appeals, and more letters of medical necessity to get the needed equipment.
- Specific assistance available to those just over the poverty line and the middle class. These are people who have to pay out of pocket or have such a deductible that it puts the whole family at risk.
- More funding for supported living arrangement to include all populations including those with mental health challenges
- Schools should have a pamphlet with a list of contact info for each area of need (for the child and family) that is probable after leaving high school.
- Closing tax loopholes, prosecuting corporate tax evasion and dismissal from public office those whose conflict of interest compromises the general welfare of the people for private profit
- To begin this earlier and collaborate with all services (psychology, pt/ ot/st, social work, parents, medical doctor, etc.)
- Rework the system of allocating funds so that more dollars trickle down to the people that it was intended for.
- Greater understanding from the Medicaid office that not all clients are able to receive the call from their office.
- If I didn't have to worry about Medicaid and social security (SSI) it would help allot. Also finding an employer who was willing to give me a chance would be nice too.
- All new housing to feature universal design, steeples entry, wide hallways, wide doorways and accessible bathroom. This would allow homeowners to age in place.
- Make it a rule that she has to keep clean, no matter what. I think the restraint that is like a tray that goes on wheelchairs would be helpful. The nursing home has an alarm if they move out of their seat, but if they fall this does not seem to help situation
- When IEP's are developed for any person, some measurable goal will be attached. Not just graduation, but graduating with further expectations. Learning to take responsibility for one's own actions/behaviors
- Complete integration into school and the community is the best way to change attitudes and education.
- To have services to be culturally accessible for deaf population, to be done in direct services by deaf professional
- Require all service providers, especially doctors, to provide all information and all options on those

services

- More new construction using universal design concepts, and more effort to make public assistance available for low income persons.
- Career planning, internships, volunteer experiences at the junior high and senior high school levels. Mentoring programs. Making post-secondary education an option for more persons with disabilities.
- For his person centered plan to be funded and services documented as needed be provided so that he may live his final years in his own home
- That the local government that I worked for had to make restituted back pay, with interest, & also had to put me back to work, in some sort of job where I can continue to contribute to society, instead of being a financial burden.
- Thinking outside the box on employment for individuals with disabilities. Not all individuals want to be a greeter or bagger.
- If society could be made to realize that you don't have to have a high IQ in order to be a valuable member of society
- To enforce the mandates for removal or architectural barriers on a state wide level through fines and punitive action, because administrative pleading hasn't worked in the last 21 years. Ada compliance is another cost of doing business, not an inconvenience. Training and random guest shopper training for employment in sensitivity and the law regarding those with disabilities.
- They should ask for the teachers, the specialists, the aids, the specialists outside of school, the parents, and maybe even the child where we think the child should be placed and take it all into consideration. Take into consideration the opinion of everyone who spends time with the child the most. Even the child his/herself.
- Training of employers. They are not willing to hire blind/vision impaired even though the person has all the equipment and software already and that would not be the barrier. They are just very unwilling to hire anyone with vision impairment.
- Children would be educated with their peers with the appropriate supports and services in place. If this is not done, how do those peers grow up to be adults that are willing and ready to support adults with disabilities in their communities? If we don't teach the value of all people at young ages, we have little hope for different worlds for our adults with disabilities!
- Have the companies and or businesses buy and offer motorized carts, or wheel carts. Or offer some other type of transportation (golf carts) in and about the businesses. Plus make the shelves more reachable for people who are using the wheel chairs and motorized carts, because nine times out of ten the items you need is on the top shelves.
- A blending of old and new ways of case management to build trust and strong teamwork for consumers
- Even though your child doesn't have a diagnosis there should be help for families with a child with a medical condition to be able to get assistance.
- Work with me as I have worked throughout my life but now the disabilities have taken its toll on me. I fear I will lose any assets such as 401k set aside.
- When an agency allows this to occur where stealing is done in the home. They need to cut off state money. Policy should be in place and the person needs to be prosecuted. That is wrong.
- A person-centered approach to planning where the individual is a part of the process and attends meetings where decisions are being made about them.
- One pot of money - divided equally per child with hearing loss. Currently there is one pot for Indiana school for the deaf which doesn't serve children in the mainstream directly. The doe has another pot but

it's not equal to ISD's \$ per student.

- Voc rehab counselors shouldn't assume that the client is finished with services when really nothing has been done in the first place.
- Acquiring appropriate roommates in a Medicaid waiver home with consistent and appropriate staffing.
- Provide group and one-on-one education for those who will be interacting and working and living with people who have disabilities
- Obtaining community compliance with the ADA - the more prevalent pwd are in their communities, the greater the increase in overall acceptance and inclusion by the general public
- Accountability to have 100 % participation from school instructors and instructors aids and hold them accountable for actually following through student IEP and to show progress on paper and scribe for student if need be and take student notes; not just sit in with student and day dream this is no service to the student and is a waste of time and money for student and school alike. It's a shame this happens year after year, just because we have no real way of monitoring these instructors' assistants and teacher they are getting away with it. Also, verbal humiliation of teachers and assistant to spec education students while in class in from of peers! Should not be tolerated but reported if teacher/teachers get caught. Accountability! Cameras should be used in all classes and parents allowed to view when requested for proof. Should be a law for this to be done ASAP and needed for the student's protection most importantly.
- IndyGo using the buses more efficiently by picking up and dropping off customers and not passing their destination to pick up someone farther away and doubling back for drop off. Require taxi drivers to pick up customers with vouchers or stop offering them. It is currently money wasted as the drivers say they don't make enough money off the fares.
- A good first step would be for more people with disabilities to obtain jobs in the community, thereby enabling their financial independence and greater acceptance by the community at large; of course education is key to making this step forward.
- Require the state to fund and all service providers to treat the whole person who has more than one diagnosed disability or medical condition.
- An easy to read and comprehend pamphlet or print out that explains the programs and their impact or interaction with other services.
- An understanding and community involvement with people with disabilities in the areas of emergency management
- Establishment of preferences for people who are institutionalized and connected with money follows the person within the USDA rural development rental housing developments, section 8 housing choice voucher programs through all Indiana public housing agencies (including IHODA), access to home/TBRA for bridge subsidies and/or permanent subsidies, increased percentage of LIHTC units affordable to those with SSI level of incomes.
- To allow the disabled back on the lists, it was noted this was at the discretion of the apartment complex owners it seems to me it is the same is discrimination.
- If agencies (including aps) would actually do their job and get involved when a person with disability has been abused/neglected
- Indiana teachers need to understand how to work with children with disabilities and help them to be successful in the classroom. More teachers training, more paraprofessionals available.
- My doctor's word should be good enough. It should not be left up to a board or a judge to determine if I am disabled. I need to know what services are out there for me without having to spend weeks searching and calling to find out that fibromyalgia is not considered a disability, or that just because a doctor says my back is not bad enough for surgery that it doesn't hurt. Tell the disabled there is help out there and

where to find it.

- Making vans parking spots strictly vans with wheelchair lifts and making all businesses ADA assessable
- Increasing funding for public transportation and making sure that fund are actually used for accessible mass transit systems throughout the state.
- Offering low cost treatment options, availability of programs in the community for non-charged individuals
- Local BDDS should let more people know about their services and allow res programs to inform when questioned
- Continue to allow Medicaid waivers to support transportation to work when other subsidized transportation is not appropriate
- I feel that all places of business should include a section in their training that addresses people with disabilities, if the place of business has personal contact with people in the public.
- Need to have business who will hire people for about 4 hours a day for 2 to 4 days a week. I can't handle more than that due to disability issues.
- If we can't increase staff, in most situations adding electronic monitoring would help--that way, especially for those individuals who cannot communicate easily, you can be sure no abuse is occurring. There also needs to be an exception in staffing budgets for those individuals who are dangerous to themselves and others, and more than 1 staff should be present during all awake hours.
- Someplace to go, or someone to call, who has all the information available and is willing to spend time and share their knowledge with the people who need it.
- Ideally safeguards are in place. People vetted to work with adults with disabilities should have impeccable screening and there should be some kind of representative to work with the family to ensure safety with family members as well.
- Allow both parents to be able to give care, or pay us directly and get rid of agencies. Pay us to self-direct cut out the middle men.
- A greater willingness for quality employers (i.e., a law firm, in my instance) to hire employees with disabilities
- Provide incentives to employers for hiring individuals with developmental disabilities; use person centered planning to target businesses that would benefit from incentives on a case-by-case basis.
- All the counselors to be training with ADA to treat the disabilities in a proper way to meet their effective communication.
- Centralized tracking of all service providers for the individual and understanding of the scope/services/responsibilities of each provider.
- The different state agencies need to be more open with benefits that exist. When I go in person to my local FSSA
- Office I should be able to access whether I have dental benefits, glasses, place on waiting list, etc. You have to make too many phone calls and still can't find info. State government should hire disabled people and mandate that local government have a percentage of their work force filled with people who have disabilities. When I lived in WA. State I had a job with the public works dept. Of Snohomish co. As their mail carrier and was given the responsibility of sorting and delivering the mail to 10 floors of the building, I had access to public transportation and was able to lead a much more independent life. I had a case worker that could answer my questions without a hassle and work opportunities provided me with the necessary support. Indiana does not meet the needs of a disabled person.

- Allowing all children from same family to be together in same schools and not split apart; it just makes everything harder on family and points out how "different" our special needs child is compared to others and other families
- When building or renovating a sidewalk or building realize that people in wheelchairs need ramps space to turn when entering a door and allow for space to move around in buildings and restaurants
- Help us families that need an attorney so we can make in no we mean business and take due process from families that are poor more serious
- More one-on-one assistance with case workers /benefit representatives to work through benefit processing instead of different persons.
- A statewide program that establishes guardianships for individuals that cannot give consent to treatments.
- Schools would be adequately funded to fully implement the children's social, emotional, behavioral health plan.
- It would be great if all cinemas that allow the public at large be required to purchase open-caption devices that can fit into the cup holder. Then all captioning will be made for the deaf without the distraction for hearing people who do not wish to read the words. They can look up at the screen and not have interference of words at the bottom of the screen.
- Budgets large enough to support individuals in a truly independent setting or a network system set up to find compatible roommates rather than just throwing people around like they are furniture.
- More services and care provided by health insurance and Medicaid, and education services/support for preschoolers age 3-6. Since many children don't get identify with problems until the child is over the age of 3, they don't get early enough help with education/social pre-school, medical and mental health treatment and therapy.
- Requiring all places, regardless of the age of the business, to become handicap accessible for all people with disabilities.
- Supports should focus on allowing the disabled individual to achieve at the highest level, rather than aiming as though the person is not able and must be warehoused either in actuality or in supports
- Establishing higher expectations for outcomes and aligning services and policies to those expectations.
- For an adult protection agency to respond, investigate, and determine if the situation warrants intervention.
- Funding to pay for these extra qualified resources in the classrooms. If we want to choose a smaller school to reduce the potential for bullying, the resources aren't available in the majority of the smaller, private and rural schools.
- The state has no one designated to reach out to school-aged children/families to educate them about waivers at IEP's. Neither BDDS nor VRS attends IEP's, neither do they otherwise "market" services to students/individuals or their families. Teachers are not typically well educated on the waivers or VRS and are not equipped to explain to families how to sign up or express why they should be signing up. As provider, I have been filling this gap within our counties of service to assure students/individuals have a fighting chance to obtain needed services. In our counties, BDDS's and VRS leaves business cards for BDDS and VRS at IEP's, neither service area maintains a presence at these important planning meetings.
- If prospective employee demonstrates can perform job duties then to be hired regardless of employer's fear, for example. Of liability (individual might fall etc.)
- Use of computer outside of work or scheduled uninterrupted work time to complete assignments. Discursions when disclosure of personal issues.

- Keep hospitalized until the doctor says they are ready to leave not just because the insurance runs out.
- Recruitment and training of qualified individuals to implement programming needs based off the consumers goals
- Many more IPAS employees to help with legal and insurance aspects that people with disabilities face.
- No Obama Care

Respondent Demographics

8. Please select the statements that best describes you:

Person Completing Survey	n	%
Someone who works in the disability field	158	33%
A family member of an individual with a disability occurring after age 22	143	30%
An individual with a disability (occurred after the age of 22)	52	11%
An individual with a developmental disability (disability occurred on or before age 22)	40	8%
A family member of an individual with a developmental disability or who has a significant mental illness or emotional impairment	24	5%
Someone who works in another field, not in a disability field	24	5%
A professional or other person completing the survey	16	3%
An individual with a significant mental illness or emotional impairment	12	3%
An individual with a traumatic brain or head injury	12	3%
Total	481	100%

9. Is your ethnic background Latino or Hispanic?

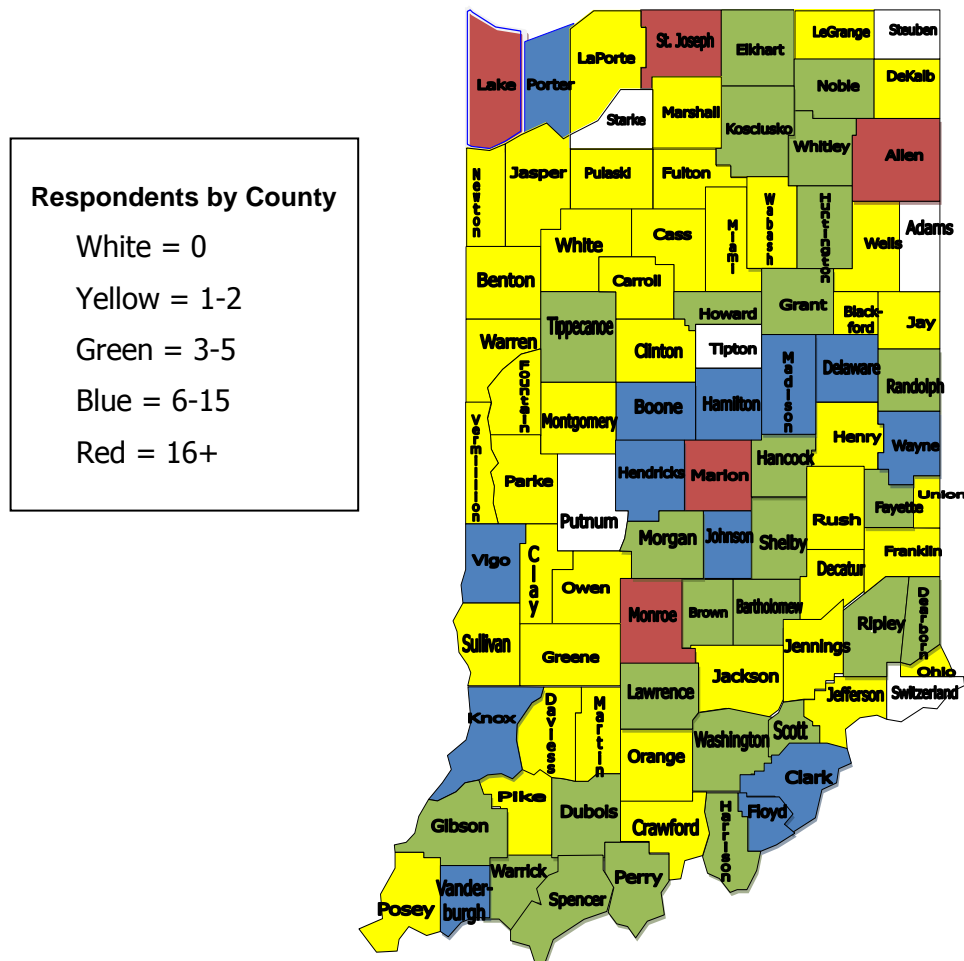
Latino or Hispanic	n	%
Yes	9	2
No	460	98
Total	469	100%

10. Please indicate what best describes your racial background:

Race	n	%
White/Caucasian	423	90%
Black/African American	29	6%
Other	17	4%
Native American	10	2%
Asian/Pacific Islander	2	<1%
Total	481	100%

11. Please select your county or residence:

In 2006 survey, 155 individuals from 49 counties responded to the survey. In the 2011 survey, responses were collected from 503 individuals; representing 87 of Indiana 92 counties (95%).



Counties	N
Allen County	38
Bartholomew County	5
Benton County	1
Blackford County	1
Boone County	9
Brown County	5
Carroll County	1
Cass County	1
Clark County	8
Clay County	2
Clinton County	2
Crawford County	1
Daviess County	1
Dearborn County	5
Decatur County	1
DeKalb County	2
Delaware County	14
Dubois County	5
Elkhart County	5
Fayette County	5
Floyd County	11
Fountain County	2

Counties	N
Franklin County	2
Fulton County	2
Gibson County	3
Grant County	3
Greene County	2
Hamilton County	13
Hancock County	3
Harrison County	3
Hendricks County	8
Henry County	1
Howard County	5
Huntington County	3
Jackson County	2
Jasper County	1
Jay County	1
Jefferson County	1
Jennings County	1
Johnson County	12
Knox County	6
Kosciusko County	5
LaGrange County	2
Lake County	35

Counties	N
LaPorte County	2
Lawrence County	5
Madison County	6
Marion County	76
Marshall County	1
Martin County	2
Miami County	2
Monroe County	27
Montgomery County	2
Morgan County	4
Newton County	2
Noble County	5
Ohio County	2
Orange County	1
Owen County	2
Parke County	2
Perry County	4
Pike County	1
Porter County	7
Posey County	2
Pulaski County	1
Randolph County	3

Counties	N
Ripley County	5
Rush County	1
Scott County	3
Shelby County	3
Spencer County	3
St. Joseph County	16
Sullivan County	1
Tippecanoe County	4
Union County	1
Vanderburgh County	8
Vermillion County	1
Vigo County	12
Wabash County	1
Warren County	1
Warrick County	3
Washington County	3
Wayne County	14
Wells County	1
White County	2
Whitley County	3
I do not live in Indiana	1
Total	485

Appendix A

2011 IPAS Critical Barriers Survey Instrument

ABUSE and NEGLECT

Below you will find 5 categories of services and supports for people with disabilities in Indiana. For each category, we ask you this question: If IPAS could work on only three barriers in each category, which three would you recommend we focus on?

CATEGORY 1: ABUSE and NEGLECT - Working to reduce incidents of abuse (i.e., abuse as perpetrated by staff members providing services to individuals with disabilities) and neglect is a primary function of IPAS. Experiencing abuse or neglect represents a fundamental barrier to living an independent and productive life.

Please check your THREE most important barriers for IPAS to target related to ABUSE and NEGLECT: (You may choose up to three)

- ☐ Physical/sexual assault or harassment
- ☐ Inappropriate/excessive use of physical restraints
- ☐ Isolation/seclusion
- ☐ Verbal abuse
- ☐ Inappropriate/excessive use of medication
- ☐ Financial exploitation or coercion
- ☐ Suspicious death
- ☐ Personal care (hygiene, clothing, food, shelter)
- ☐ Personal rehabilitation/vocational programming
- ☐ Release from institution
- ☐ Other abuse (please specify)

TREATMENT RIGHTS

CATEGORY 2: TREATMENT RIGHTS - Individuals with disabilities have the right to receive appropriate treatment that should be designed to maximize the potential of the individual and should be provided in the setting that is least restrictive of the individual's personal liberty. Failure to receive appropriate and effective treatment that is provided in the least restrictive environment represents a fundamental barrier to living an independent and productive life.

Please check your THREE most important barriers for IPAS to target related to TREATMENT RIGHTS: (You may choose up to three)

- ☐ Failure to provide appropriate medical treatment
- ☐ Diagnostic/other medical evaluations (not treatment)
- ☐ Failure to provide appropriate mental health treatment
- ☐ Diagnostic/other mental health evaluations (not treatment)
- ☐ Admission to residential or inpatient care
- ☐ Discharge planning
- ☐ Written habilitation plan
- ☐ Commitment/Recommitment
- ☐ Other treatment rights (please specify)

EDUCATION

CATEGORY 3: EDUCATION - Students with disabilities have the right to receive a Free and Appropriate Education (FAPE). Education that is not appropriate to the needs of the student or that is not provided in the most integrated setting represents a significant barrier towards receiving a FAPE and ultimately to living an independent and productive life.

Please check your THREE most important barriers for IPAS to target related to EDUCATION: (You may choose up to three)

- ☐ Discipline/suspension/expulsion
- ☐ Assistive technology services and devices
- ☐ Least restrictive environment
- ☐ Physical access
- ☐ Multidisciplinary evaluation/assessments
- ☐ Violation of procedural safeguards
- ☐ Eligibility
- ☐ Individual Education Plan (IEP) planning/development/implementation
- ☐ Individual Family Service Plan (IFSP) planning/development/implementation
- ☐ Functional Behavioral Assessment (FBA) planning/development/implementation
- ☐ Transition planning (from school to work)
- ☐ Other education (please specify)

ACCESS TO SERVICES

CATEGORY 4: ACCESS TO SERVICES - Individuals with disabilities have the right to a wide range of services and supports. Lack of appropriate services and supports, provided in a manner that maximizes potential and is provided in the setting that is least restrictive of the individual's personal liberty or reduces the choices open to people with disabilities about where they live, work, and play. Lack of basic services represents significant barriers that can result in isolation rather than full integration and inclusion in the mainstream of society.

Please check your THREE most important barriers for IPAS to target related to ACCESS TO SERVICES: (You may choose up to three)

- ☐ Mental health care
- ☐ Community living
- ☐ Inclusive child care
- ☐ Personal assistant services
- ☐ Person-centered planning
- ☐ Assistive technology devices and services
- ☐ Interpreter service
- ☐ Access to government services
- ☐ Other access issues (please specify)

OTHER RIGHTS ISSUES

CATEGORY 5: OTHER RIGHTS ISSUES - Various state and federal laws, rules, and regulations provide individuals with disabilities access to appropriate services (e.g. reasonable accommodation). Lack of information regarding these rights can represent a significant barrier to living an independent and productive life.

Please check your THREE most important barriers for IPAS to target related to OTHER RIGHTS ISSUES: (You may choose up to three)

- ☐ Health care
- ☐ Problems with guardian/conservator
- ☐ Other personal decision making issues
- ☐ Denial of recreational opportunities
- ☐ Denial of access to records/corrections
- ☐ Denial of visitors
- ☐ Denial of privacy
- ☐ Breach of confidentiality (of records)

- ☐ Denial of parental/family rights
- ☐ Public accommodations
- ☐ Architectural Barriers (ADA)
- ☐ Accessible housing (ADA/Fair housing)
- ☐ Subsidized housing (Section 8)
- ☐ Other housing issues
- ☐ Access to transportation (ADA)
- ☐ Employment: disability discrimination
- ☐ Medicaid or Medicare issues
- ☐ Failure to obtain informed consent
- ☐ Consumer or family participation in treatment planning
- ☐ Do Not Resuscitate (DNR) orders
- ☐ Advanced directives
- ☐ Use of accessible parking
- ☐ Use of service animal
- ☐ Voting
- ☐ Other rights violations (please specify)

OTHER RIGHTS ISSUES

You selected "Other Housing Issues" in the question above, please specify the issue here:

You selected "Other Personal Decision Making Issues" in the question above, please specify the issue here:

(BARRIERS AND SOLUTIONS)

What do you see as the greatest rights barrier for you, your family member, or for those you represent?

What would be the ideal solution regarding your comments above?

A Little Bit about You (Demographic Section)

Please select the statements that best describe you. (Please check only one)

- ☐ an individual with a developmental disability that occurred on or before age 22
- ☐ an individual with a disability that occurred after the age of 22
- ☐ an individual with a significant mental illness or emotional impairment
- ☐ an individual with a traumatic brain or head injury
- ☐ an individual with HIV/AIDS
- ☐ a family member or a guardian of an individual who is labeled mentally ill or emotionally disturbed
- ☐ a family member or a guardian of an individual with a developmental disability that occurred on or before age 22
- ☐ a family member or guardian of an individual with a disability that occurred after age 22
- ☐ Someone who works in the disability field
- ☐ Someone who works in another field, not in a disability field

Is your ethnic background Latino or Hispanic? (Please check only one)

- ☐ Yes
- ☐ No

Please indicate your racial background. (Please check all that apply)

- ☐ Asian/Pacific Islander
- ☐ Black/African American
- ☐ Native American
- ☐ White/Caucasian
- ☐ Other (please specify _____)

Please select your county of residence. (This is a required question)

County of residence _____

Appendix B

Glossary of Terms and Acronyms

Below are a list acronyms or abbreviations used by some respondents in the IPAS Critical Barriers Report.

DME - Durable Medical Equipment

IEP - Individualized Education Program/Plan

RTI - Response to Intervention

GED - General Education Development

OT - Occupational Therapy/therapist

PT - Physical Therapy/therapist

SLP - Speech Language Pathologist

ABA - Applied Behavior Analysis

FBA - Functional Behavior Analysis

FBP - Functional Behavior Plan

TANF - Temporary Assistance to Needy Families

PWD/PWDs - People with Disabilities

Other useful acronyms and abbreviations by category

– A – Adult

AF/A - Alternative Family for Adults

IHP - Individual Habilitation Plan

IL - Independent Living

IHP - Individual Habilitation Plan

ILC - Independent Living Center

ILP - Integrated Living Plan

IPP - Individual Program Plan

ISP - Individual Service Plan

SILP - Semi-Independent Living Program

VR - Vocational Rehabilitation

– A – ASSISTIVE TECHNOLOGY

AAC - Augmentative Alternative Communication

AT - Assistive Technology

aug. com. - Augmentative Communication

f/c - facilitated communication

VI/VO - Voice Input/Voice Output

TDD - Telecommunications Device for the Deaf

TT - Text Telephone

TTY - Teletypewriter

– C – COMMUNICATION

AAC - Augmentative Alternative Communication

aug. com. - Augmentative Communication

DVS - Descriptive Video Service

f/c - facilitated communication

TDD - Telecommunications Device for the Deaf

TT - Text Telephone

TTY - Teletypewriter

VI/VO - Voice Input/Voice Output

– D – DIAGNOSTIC/EVALUATION

ADI-R - Autism Diagnostic Interview - Revised

ADOS - Autism Diagnostic Observation Schedule

CARS - Childhood Autism Rating Scale

CAT - California Achievement Test

D & E - Diagnostic Evaluation

FLS - Functional Limitation Screen

ISTEP - Indiana State Testing Evaluation Program

PL-ADOS - Pre-Linguistic Autism Diagnostic Schedule

SB:4 - Stanford Binet Intelligence Scale: Fourth Edition

WAIS - Wechsler Adult Intelligence Scale

WISC - Wechsler Intelligence Scale for Children

– D – DISABILITIES

AD - Alzheimer's Disease

ADD - Attention Deficit Disorder

ADHD - Attention Deficit Hyperactivity Disorder

ALS - Amyotrophic Lateral Sclerosis

AU - Autism

BD - Behavior Disorder

CFS - Chronic Fatigue Syndrome

CP - Cerebral Palsy

DB - Deaf Blind (dual sensory impairment)

DD - Developmental Disabilities

DS - Down Syndrome

EBD - Emotional Behavior Disorder

EH - Emotional Handicap

FAE - Fetal Alcohol Effect

FAS - Fetal Alcohol Syndrome

HI - Hearing Impaired

LD - Learning Disability

MD - Muscular Dystrophy

MH - Mental Handicap

MiMH - Mild Mental Handicap

MoMH - Moderate Mental Handicap

SMH - Severe Mental Handicap

S/P - Severe/Profound

MI - Mental Illness

MR - Mental Retardation

MR/DD - Mental Retardation/Developmental Disability

MS - Multiple Sclerosis

MULTI - Multiple Handicap

NBD - Neurobiological Disorders

OCD - Obsessive-Compulsive Disorder

ODD - Oppositional Defiant Disorder

OHI - Other Health Impairment

OI - Orthopedically Impairment

PDD - Pervasive Developmental Disorder

PDD/NOS - Pervasive Developmental Disorder Not Otherwise Specified

SFL - Substantial Functional Limitation

SLD/LD - Specific Learning Disability

TBI - Traumatic Brain Injury

TS - Tourette Syndrome

VI - Visual Impairment

– E – EARLY CHILDHOOD

EC - Early Childhood

EI - Early Intervention

ECSE - Early Childhood Special Education

IFSP - Individualized Family Service Plan

NICU - Neonatal Intensive Care Unit

– F – FEDERAL ORGANIZATIONS

ACY - Administration on Children and Youth

ADD - Administration on Developmental Disabilities

ATBCB - Architectural and Transportation Barriers Compliance Board

DOE - Department of Education

DOJ - Department of Justice

EEOC - Equal Employment Opportunity Commission

HHS - Health and Human Services

OCR - Office of Civil Rights

OSEP - Office of Special Education Programs

OSERS - Office of Special Education and Rehabilitation Services

–H – HOME & COMMUNITY SERVICES

AF/A - Alternative Family for Adults

AF/C - Alternative Family for Children

BAIS - Bureau of Aging & In-Home Services

CM - Case Manager

DME - Durable Medical Equipment

HHA - Home Health Agency

HSA - Home Service Agency

ICF - Intermediate Care Facility

ICF/MR - Intermediate Care Facility for Mental Retardation

MFC - Medically Fragile Children

PWD/PWDs - People with Disabilities

S.B. 30 - Provision that excludes parental income and resources for recipients under 18 on the ICF/MR and MFC waivers

TANF - Temporary Assistance to Needy Families

– I – INDIANA

ASK - About Special Kids (formerly the Indiana Parent Information Network -IPIN)

Attain - Overcoming Functional Limitations (formerly Accessing Technology Through Awareness in Indiana)

ATTIC - Assistive Technology, Training and Information Center

CCA - Bloomington's Council for Community Accessibility

COVOH - Council of Volunteers and Organizations for Hoosiers with Disabilities

GCPD - Governor's Council for People with Disabilities

ICOIL - Indiana Council on Independent Living

INARF - Indiana Association of Rehabilitation Facilities, Inc.

IN*SOURCE - Indiana Resource Center for Families

IPAS - Indiana Protection and Advocacy Services

IPIN - Indiana Parent Information Network - see ASK

IRCIL - Indianapolis Resource Center for Independent Living, Inc.

SICIL - Southern Indiana Center for Independent Living

UTS - Unified Training System

UW - United Way

– I – Indiana Institute on Disability And Community Centers

CAC - Center on Aging and Community

CCLC - Center on Community Living and Careers

CeDIR - Center for Disability Information & Referral

CELL - Center on Education and Lifelong Learning

CPPS - Center for Planning and Policy Studies

ECC - Early Childhood Center

FIRST - Family and Individual Resource and Support Team

IRCA - Indiana Resource Center for Autism

ITP - Interdisciplinary Training Plan

NIRS - National Information and Reporting System (formerly TIS)

OVPR - Office of the Vice President for Research

UCE (also UCEDD) Indiana's University Center for Excellence on Disabilities

– L – LEGISLATION

504 - Section 504 of the Rehabilitation Act of 1973

508 - Section 508 of the Rehabilitation Act of 1973

ADA - Americans with Disabilities Act

ARTICLE 7 - Indiana's Special Education Rules

FERPA - Family Education Rights and Privacy Act of 1974

H.B. - House Bill

IDEA - Individuals with Disabilities Education Act (101-476, formerly known as P.L. 94-142)

P.L. - Public Law

S.B. - Senate Bill

TANF - Temporary Assistance for Needy Families

– M – Mental Illness

NAMI Indiana - National Alliance on Mental Illness

– M – MISCELLANEOUS

AB- Adaptive Behavior

AIT - Auditory Integration Training

AT - Auditory Training

CHINS - Children in Need of Services

LOC - Level of Care

MAPS - McGill Action Planning System - futures planning for children

PA - Prior Authorization

Sib - Sibling

SIB - Self Injurious Behavior

TA or T/A - Technical Assistance

QMRP - Qualified Mental Retardation Professional

– N – NATIONAL ORGANIZATIONS

AAA - Area Agency on Aging

AAMR - American Association on Mental Retardation

AFB - American Foundation for the Blind

APSE - Association for Persons in Supported Employment

The Arc - (formerly Association for Retarded Citizens)

ASA - Autism Society of America

ASHA - American Speech/Hearing Association

AUCD - Association of University Centers on Disabilities

CHADD - Children and Adults with Attention Deficit Disorder

CEC - Council for Exceptional Children

EASI - Equal Access to Software and Information

LDA - Learning Disability Association

MAAP - More Advanced Autistic People

NAD - National Association of the Deaf

NDSC - National Down Syndrome Congress

NDSS - National Down Syndrome Society

NICHCY - National Information Center for Children and Youth with Disabilities

NARIC - National Rehabilitation Information Center

NORD - National Organization for Rare Disorders

SHHH - Self Help for Hard of Hearing People

TASH - (formerly The Association for Persons with Severe Handicaps)

UCPA - United Cerebral Palsy Association

– P – PARENT INVOLVEMENT

ASK - About Special Kids (formerly the Indiana Parent Information Network -IPIN)

CHADD - Children and Adults with Attention Deficit Disorder

IN*SOURCE - Indiana Resource Center for Families

IPIN - Indiana Parent Information Network - see ASK

MUMS - Mothers United for Moral Support

NPN - National Parent Network

PAC - Parent Advisory Council

– P – PUBLIC SCHOOLS

APE - Adaptive Physical Education

ACR - Annual Case Review

APT - Assistant Physical Therapist

CBI - Community Based Instruction

CCC - Case Conference Committee

DOE - Department of Education

CSPD - Comprehensive System of Personnel Development

FAPE - Free Appropriate Public Education

GED - General Education Development

GEI - General Education Intervention

HB - Homebound

IEE - Independent Education Evaluation

IEP - Individualized Education Program

IHO - Independent Hearing Officer

ISB - Indiana School for the Blind

ISD - Indiana School for the Deaf

ITP - Individualized Transition Plan

LEA - Local Education Agency

LRE - Least Restrictive Environment

NPR - Notice of Parent Rights

PAC - Parent Advisory Council

REI - Regular Education Initiative

RTI - Response to Intervention/Instruction

SEA - State Education Agency

SPED - Special Education

–R– RELATED SERVICES

ABA - Applied Behavior Analysis

FBA - Functional Behavior Analysis

FBP - Functional Behavior Plan

OT - Occupational Therapy/Therapist

OTA - Occupational Therapist Assistant

PT - Physical Therapy/Therapist

PTA - Parent Teacher Association

PTA - Physical Therapist Assistant

RT - Recreation Therapist

SLP - Speech Language Pathologist

SLT - Speech Language Therapist

–S– SOCIAL SECURITY

IRWE - Impairment-Related Work Expenses

PASS - Plan for Achieving Self-Support

SSA - Social Security Administration

SSDI - Social Security Disability Insurance

SSI - Supplemental Security Income

– S– STATE AGENCIES

BAIS - Bureau of Aging & In-Home Services

BDDS - Bureau of Developmental Disabilities Services

DCS - Department of Child Services

DDARS - Division of Disability, Aging and Rehabilitative Services

DFR - Division of Family Resources

DOE - Department of Education

GCPD - Governor's Council for People with Disabilities

IFSSA or FSSA - Indiana Family and Social Services Administration

ISDH - Indiana State Department of Health

P&A - Protection and Advocacy